

March 1995

Clinical Center News

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KEEP A
WATCHFUL

eye

ON PATIENTS'
RECORDS.



Don't leave confidential files or charts
unattended.

confidentiality

IT'S EVERYBODY'S BUSINESS!

CONFIDENTIALITY EDUCATION GROUP

Confidentiality

It's everybody's business. Safeguarding patient privacy is the responsibility of every Clinical Center employee. The CC Confidentiality Education Group's poster campaign is designed to help spread the word. This is the second poster in a four-part series now on display here to focus attention on the issue.

Neumann on presidential committee investigating Cold War experiments

A Clinical Center physician is wrapping up his work for a presidential advisory committee examining the government's role in radiation experiments involving humans during the Cold War years.

Dr. Ronald Neumann, chief of the Nuclear Medicine Department, has been detailed part-time to the Advisory Committee on Human Radiation Experiments for the past year. The committee was formed last March to review the ethical and scientific standards used in government-sponsored human experiments involving radiation exposure. Details of many of the experiments had been classified until recently because of national security concerns.

The committee, a 14-member team of nationally recognized experts in bioethics, epidemiology, history, law, radiation therapy, radiation biology, and nuclear medicine, has several goals, Dr. Neumann explains. "One is to look in detail at ethically questionable experiments to see if there is reason to believe individuals may have suffered harm and to make a decision about offering some form of remedy to them or their families."

A second goal is to determine if policies and rules in place at the time of the experiments were followed. "That means we've had to spend a great deal of time constructing a

history of medical ethics."

A third goal is to find out if regulations now in place effectively protect current research patients and to recommend changes in policy, if necessary.

The committee's investigations focus on government-conducted or sponsored experiments between 1944 and 1974 with ionizing radiation and certain intentional releases of radiation into the environment. The group will recommend to the Human Radiation Interagency Working Group how to address any abuses found in past experiments and, if necessary, new policies to improve ethical practices in today's research.

The interagency group is made up of the heads of the agencies that carried out or sponsored the experiments—Defense, Energy, Health and Human Services, Veterans Affairs, the Central Intelligence Agency, and National Aeronautics and Space Administration—along with the chiefs of the Office of Management and Budget and Justice.

Combing government documents for research records was the committee's initial agenda. "Each agency created a group to look for documents in their own archives. All have been cooperative to an extent," Dr. Neumann says.

Continued on page seven

CC director addresses concerns, answers questions

(Editor's note: Dr. John Gallin, CC director, asked employees to send him job-related concerns and questions following the Jan. 20 town meeting. *CCNews* will print Dr. Gallin's responses in a periodic series that begins this month.)

(Comment) "I am concerned about the general appearance of the Clinical Center. It's dirty. The premier research hospital should sparkle. First impressions count." and "Over the past three to five years the phrase 'failing infrastructure' has become a common description for building 10. Unfortunately it has also become an excuse for why things can't be fixed and why things are too hard to keep clean. No one expects miracles, but we can do better. Will you help us to change this prevailing attitude?"

(Dr. Gallin) A number of employees have expressed concerns about the appearance of the Clinical Center. They are concerns I share. When patients, families, and visitors walk through our doors, it is imperative that their first impression of the Clinical Center be a positive one. If it's not, it will be harder for all of us to earn their trust and respect as caregivers and scientists.

The CC's top managers and Housekeeping and Fabric Care Department staff are working closely to develop new ways to approach the daily tasks necessary to keep the building clean. We are pursuing imaginative ways to assist housekeeping with their task. But each CC employee shares in this responsibility. I urge each of you to take a few minutes each day to make your personal work area a neater place. If you see an area anywhere in the Clinical Center that needs extra cleaning, bring it to the attention of the housekeeping department.

As we begin planning and work on the new hospital module, it will

become increasingly important to protect and preserve our existing space. I anticipate your cooperation and encourage your suggestions on how to do a better job.

(Comment) "Town meetings should be videotaped and dispersed to services within the Clinical Center."

(Dr. Gallin) The town meeting on Jan. 20 was videotaped, and future meetings will be as well. Copies are available from Clinical Center Communications. Call 496-2563 to request a copy.

(Comment) "I wanted to thank you for having the town meeting. It was very informative and helpful. Thanks for your openness to questions, concerns, and suggestions."

(Dr. Gallin) I believe that such meetings are essential to an organization as large as this one, and I

am gratified that my initial town meeting was well-attended. The questions and comments it generated have been both informative and useful for me. I plan to continue to have at least two CC-wide town meetings a year so that I can provide details on our plans, progress, and concerns. Additional meetings will be held, if necessary.

I maintain an open-door policy as director of the Clinical Center. Your attendance at these meetings is an important aspect of that policy. Another critical aspect is hearing from you about concerns and questions throughout the year. E-mail is welcome.

To be effective, communications between an organization's director and the front-line employees must flow in both directions. I am committed to keeping CC employees informed about plans and issues that affect them. I also need to know what your concerns are and what interferes with your ability to do the best job you can.

working

Communicating better helps build teamwork

Here are some suggestions to share with team members to improve team communication and productivity:

- Avoid saying, "I don't agree," when you feel a teammate's idea won't fly. Praise the positive point of the idea first. Then offer an idea that may work better.

- Never criticize teammates' mistakes in public. You'll destroy morale and cause co-workers to lose confidence in you.

- Resist the temptation to blame others when things go wrong. Don't use "blame words."

- Avoid drifting off the subject or straying from main points when speaking to your teammates. Outline what you want to say before you speak. Tell team members how long your talk will take. Give a one-sentence overview of your message's content—and then present it logically. *(Reprinted from communication briefings)*

Clinical Center
News

Editor: Sara Byars

Clinical Center News, Building 10, Room 1C255, National Institutes of Health, Bethesda, Maryland 20892. (301) 496-2563. Fax: 402-2984. Published monthly by the Office of Clinical Center Communications, Colleen Henrichsen, chief, for CC employees. News, article ideas, calendar events, letters, and photographs are welcome. **Deadline** for submissions is the second Monday of each month.



Key recruiters honored

The Department of Transfusion Medicine honored its 75 blood donor key recruiters with a luncheon last month. Dr. Harvey Klein, department chief (standing right), welcomed the group. Speaker was key recruiter Greg Pryor, deputy chief of NIAID's contract management branch.

Key recruiters come from throughout the NIH community. They are available to answer questions about the blood donor program and alert potential donors when there is a critical blood shortage.

For details on the key recruiter program and the NIH Blood Donor Center, call 496-1048.

briefs

March 20 reception honors DTM's Davey

The Department of Transfusion Medicine will honor Dr. Richard J. Davey with a reception in the Medical Board Room March 20 from 2:30-3:30 p.m. Dr. Davey, chief of DTM's laboratory services section and associate director for technology and training, will join the staff of the American Red Cross as chief medical officer in April. Dr. Davey's Clinical Center friends and colleagues are invited. Light refreshments will be served. For more information, call 496-4506.

FOCC seeks members

Interested in taking an active role in the Friends of the Clinical Center (FOCC)? Consider applying for membership on the group's board. FOCC is a private, non-profit organization that provides emergency funds to support Clinical Center patients in times of crisis.

Money for FOCC, raised through contributions to the Combined Federal Campaign, corporate sponsorships, and fund-raising efforts such as the group's annual Great

Pumpkin Chase, have helped hold many families together during illness and treatment here. Patients who need FOCC's assistance are referred by the CC Social Work Department. The board of directors reviews and acts on all requests. Board membership is open to NIH employees and community members. For consideration, send a resume to the FOCC office in room 1C119, Building 10, by March 20.

April class offered

The education and training section, Office of Human Resources Management, will offer the course Stress Management Techniques April 5, 9 a.m.-3:30 p.m., in room 1N248. To register, call 496-1618.

Register bikes

Think spring and register your bicycle with the NIH police branch in room B3B17 in building 31. The registration forms and decals are available 7 a.m.-3 p.m. weekdays. You'll need your bike's frame number and any other identifying number, the make and style, color and size.

And while planning for better

weather, remember that a bicycle is legally a vehicle in Maryland. That means, NIH police note, that riders must obey all traffic signs and signals; ride with the traffic, as close to the right of the roadway as practical; yield to pedestrians; and pass only from the left (except when passing a left-turning vehicle or on a one-way street). Helmets are required for any rider under 18. For a copy of the booklet "A Safety Handbook for Bicycle and Moped Owners," contact Corporal Thomas Haden at 496-5685.

Women's history month kicks off March 9

Kathleen Matthews, host of the TV show "Working Woman" and co-anchor of "News 7 at 5," kicks off National Women's History Month events at NIH with a talk set for March 9, 11:30 a.m.-1 p.m., in Masur Auditorium.

Sponsors are the NIH Office of Research on Women's Health, the NIH Advisory Committee for Women, and the Office of Equal Opportunity Federal Women's Program. For more information, contact Shirley Everest at 496-4627.

Local artist shares love of creating with Clinical Center children

Spools. Sponges. Smocks. Smiles creep across wary faces as little fingers swirl into colorful pots of paint. It is a drizzly Thursday morning in the pediatric clinic recreation room as a young girl and her little sister sit together, learning printmaking from volunteer artist Susan Due Percy. It's a fairly quiet morning—some days up to a dozen kids show up—so the girls have Percy's undivided attention. Percy demonstrates patterns made by various objects, like bottle caps and macaroni. The girls have never done this before, and they are intrigued. The older child takes to it quickly, and patiently guides her baby sister's hands.

This session is one of several special leisure activities provided through the recreation therapy program on the pediatric AIDS and oncology unit at the Clinical Center. On other days, the kids might be engaged in magic therapy, pet therapy, or individual craft activities. Frances Byrd, recreation therapist, explains that a sick child's life is much more controlled than a normal child's, and peopled with more adults. Some kids may have daily blood draws, IV

placements, or have to take medicines that make them feel ill. Recreation therapy is a time during which nobody is poking them with needles, and nobody asks about their illness.

Percy agrees. "I'm here to provide an activity—a moment of distraction and pleasure," she says. "I'm one person who is not giving them a shot or testing them in some way. I'm someone they can trust and know that I'll just be a friend for that period of time." She tries to bring in a different activity each week, such as marbling, or screen printing, or clay sculpting, a favorite.

Percy is an accomplished artist who recently had a book of sketches accepted into the permanent collection of rare books at the National Gallery of Art. A printmaker and painter, her exhibits have received critical acclaim. Her involvement with the Clinical Center began in 1993, with a 10-week grant from the Montgomery County Arts Council's Outreach Program. The program is a partnership of schools, artists, teachers, libraries, community centers, and organizations working together to benefit children, primarily



In the pediatric clinic recreation room, Sasha and her mother get a much needed dose of fun after a tiring morning at the clinic.

those who are disadvantaged. After a second grant expired, Percy continued on as a volunteer.

"There's a special quality that Sue herself brings in that not everybody who walks in this world has," says Byrd. "She encourages creativity and is very accepting. Sue has this way of approaching a child in a nonthreatening manner. Whatever the child does is great. Without over-flattering them, she builds their self-esteem."

Patients' siblings are also welcome to participate in the recreation therapy programs, as they too need some relief from the stress of an illness in the family. Percy says she often does not know whether a participant is a patient or sibling, nor does she know their diagnosis. "The bottom line for me," she says, "is treating every child the same, whether they are sick or a sibling or healthy or a visitor."

The parents can benefit from these sessions as well. Percy recalls one young patient who turned to the mother of another patient during a session and said, "That's the first time I've seen you smile!" Says Percy, "Just knowing that their kids are happy—that must help the parents a little bit. It's nice to be able to facilitate that."

—by Sue Kendall



Volunteer art therapist Susan Due Percy (left) demonstrates printmaking to Sasha and her mom.

CC celebrates Children and Hospitals Week

Clinical Center celebrations for this year's Children and Hospitals Week, March 19-25, will focus on "Creating a Healing Environment."

In preparation for the week, children at the Clinical Center will be invited to participate in an art contest and to try their hand at creating a contribution for a quilt. The quilt will be on display March 19-25 outside the special events office, room 1C174. On March 13, Jim Newton and Paul Hill of the Celebration Shop, Inc., will entertain children and their families with folk songs, 2-3 p.m., in the 14th floor assembly hall.

The Blue Sky Puppet Theater will present "Lights Out on the Bunny Brothers" March 21 at 2

p.m. in the 14th floor assembly hall. The performance is sponsored by PEPCO.

A multi-cultural children's party is set for 2-3:30 p.m. on March 22, also in the hall. The party will feature foods from around the world.

Pediatric Pride Day caps the celebrations March 23. Be sure to wear your favorite or craziest hat to help celebrate.

The Association for the Care of Children's Health sponsors this annual event to help the public learn more about the unique needs of children and their families in the health-care setting.

"We're looking forward to a week filled with fun and educational events for children, their families, and



Annie

NIH staff," program planners say. Kristin Johnsen and Myra Woolery-Antill co-chair the event. Call 496-3103 for details.



Connie Lowe, issue section supervisory nurse in the Department of Transfusion Medicine, retires this month.

Expansion in role of blood services highlights Lowe's career

A steady increase in the numbers of blood donors and the department's burgeoning role in research are major changes Connie Lowe has seen in the Department of Transfusion Medicine, her professional homebase since 1982.

Lowe, issue section supervisory nurse, retires this month after a CC career than began in 1979.

"I started on the pediatric oncology unit on 2B," she says. The Laminar Airflow Units—sterile bubbles—housed patients with compromised immune systems. "Patients received high doses of chemo- and radiation therapy for some of the protocols. After that they'd spend four to six weeks in the Laminar units. We really got to know our patients during that time."

When she transferred to transfusion medicine three years later, the department was housed in the circular building at the CC's rear and the platelet center was in trailers

in the parking lot.

"In those days we were lucky to have a dozen blood donors a day," she recalls. That's not the case today. "The donor recruiters do a great job and the department is almost totally self-sufficient in meeting the Clinical Center's blood needs. We're also able to help researchers with special blood collection procedures for plasma, white cells, and platelets. We've been in the forefront for the first gene therapies, and now do all the processing for the bone marrow transplants."

The Clinical Center is a special place, Lowe says. "The doctors, patients, and families are really great. The staff is dedicated and hard working."

Kicking back tops the list of plans Lowe has for retirement. "We'll visit family, spend lots of time at the beach, and I'll hack away on the golf course," she says with a laugh.

Poison prevention

Looking over the items available from the CC Pharmacy Department in observance of Poison Prevention Week March 19-25 are Eddie Wolfe, a pharmacist in the ambulatory pharmacy section, and Juanita Savelli, head secretary in NCI's laboratory of biological chemistry. Stop by the Outpatient Pharmacy in room 1N238 that week to pick up a bottle of Ipecac syrup, the liquid treatment health professionals often advise to counter poisoning. Be sure to call a physician or poison center before administering any treatment, pharmacists advise.



Pharmacy offers tips on preventing accidental poisonings

While prevention is the best antidote for poisoning, accidental poisoning can occur in any home at any time. In observance of Poison Prevention Week, March 19-25, the ambulatory pharmacy section, CC Pharmacy Department, will offer free Ipecac syrup to NIH patients and employees with children and elderly relatives. Stop by the Outpatient Pharmacy, room 1N238, 9 a.m.-4 p.m. that week.

Ipecac syrup is the liquid treatment health professionals often advise to counter poisoning. The ambulatory pharmacy section will also offer pamphlets on poisoning and proper procedures for administering Ipecac syrup. Pharmacists will also be available to answer questions.

When Poison Prevention Week was first observed more than 30 years ago, nearly 450 children under five died each year of accidental poisoning. By 1978 that number had

fallen to 31 deaths a year. Today, more than half of all poisonings in the U.S. occur in children. The next largest risk group for accidental poisoning is the elderly.

Clinical Center pharmacists offer these tips to help prevent accidental poisonings:

- Keep items in original containers with original labels. Be sure to read labels before using the products.
- Keep a light on when giving or taking medications.
- Don't refer to medicine as candy when talking with children.
- Clean out the medicine cabinet periodically and safely dispose of unneeded and outdated medications.
- Keep all household chemical products, such as window cleaners and detergents, out of children's reach and sight. It's best to lock those products up when not in use.
- Store medicines separately

from household products.

•In the event of an accidental poisoning, first call your physician or poison center before administering any treatment.

•Write the number for your poison center on the inside cover of your phone book.

Regional poison centers, certified by the American Association of Poison Control Centers, offer free, comprehensive consultation services when a poisoning emergency occurs. The centers, staffed with highly trained pharmacists, nurses, medical toxicologists, and a network of medical consultants, manage nearly 75 percent of all reported at-home poisonings. Regional Poison Centers in this area open round-the-clock are the National Capital Poison Center at 202-625-3333 and the Maryland Poison Center at 1-800-492-2414.

by Eddie Wolfe and Thomas Dorworth
(Wolfe is a pharmacist in the ambulatory pharmacy section. Dorworth is section chief.)

... presidential committee examines government experiments

Continued from page one

Simple inventory control seems to have helped avert harm to volunteers involved in experiments using radioisotopes during the Cold War's early years, Dr. Neumann explains. The Atomic Energy Commission, forerunner of the Department of Energy, monitored distribution of isotopes and required each institute that received them to have a local review committee. "That was the first form of federally mandated peer review we are aware of," he says.

No such regulation governed experiments using X-ray radiation, Dr. Neumann points out. "I spent the bulk of my time looking into experiments involving total-body radiation exposure, exposures to radiation at levels that were potentially seriously harmful."

Patients were said to have been informed to varying degrees of the risks as study participants. Records don't exist in most instances since the experiments predated any governmental requirement for written informed consent. "There's only fragmentary evidence in medical charts and in letters and documents as to what patients were told."

The committee found that using the veil of national security to obscure public scrutiny of some experiments during the Cold War years wasn't always appropriate, Dr. Neumann explains.

"There are a number of items that were classified using the need for national security that in retrospect seem to have been classified rather because of concerns about negative public perception and the government's legal liability," Dr. Neumann says.

But, he points out, "It's difficult in retrospect to look at Cold War issues to decide now if classification was needed."

The experiments, in many cases, had solid scientific bases. The development of much of nuclear medicine is fundamentally an outcome of successful experiments

during this era, Dr. Neumann points out, as is the highly effective treatment of thyroid cancer using radioiodine. Availability of radioisotopes made possible an entire research field using tracer methodology, the cornerstone for many medical diagnostic tests in widespread use today.

The then Department of Health, Education, and Welfare issued regulations to protect research participants in 1974 and these have been applied government-wide since 1991, according to a committee spokesman. Federal laws still have rarely used provisions to classify certain research for national security reasons.

"Our democracy is a much more open process now than it was during the Cold War era," Dr. Neumann says. "That was a unique period in our history. But, it is not inconceivable that national security issues might be put forth again as a reason to do classified experiments."

"When transgressions have occurred, they seem to have been when individuals denied that openness to the public and didn't allow them to participate in the decision making, even to the extent of their decision to be part of an experiment."

That's why the committee's work is crucial—to make sure there are no loopholes in current laws that would

permit abuses. "There are laws in place now that the federal government says it adheres to, which prevent any experiments on humans from violating the principles of informed consent. We are reviewing the wording of these laws to help make sure that violations of consent couldn't happen again. More research has yet to be done to prove that it can't."

A renewed emphasis on the "informed" aspect of informed consent is one recommendation Dr. Neumann feels will be high on the list of recommendations once the committee's work concludes later this spring.

"A simple signature on a legal document is not the end point. Sick people are vulnerable. A number of concerns cloud their thinking when approached to participate in an experiment," he says. "I think physicians will want to give renewed attention to the process of informing those people about risks clearly and without pressures."

Other recommendations may address remedies for past wrongs. "Patients involved in these cases are often seeking something beyond a financial settlement in cases of wrongdoing," Dr. Neumann points out. "Some are simply asking for recognition that they participated in a good cause in the government's interest. Another remedy may be medical follow-up studies for patients still alive. Or to fund research into low-level radiation exposure because fundamentally much still is not known about the effects of human radiation at these levels."

The committee's final report is expected in late spring. All the records and documents collected and produced will then be turned over to the National Archives.

"We want the American public to feel safe in volunteering to participate in medical research of all kinds and to know that their rights will be protected," Dr. Neumann says.

—by Sara Byars

"Patients involved in these cases are often seeking something beyond a financial settlement in cases of wrongdoing."

Upgrades for CC's central elevators begin this month

The Clinical Center's central banks of elevators will begin sequential upgrades this month to make them more reliable and efficient.

"The upgrades will affect elevators in the B corridor, the D corridor, and the central bank of elevators outside Masur Auditorium," explains Ray Bowen, CC building services assistant manager. "We will begin work in the B corridor, then the D corridor, and finally the main elevator banks. Only one elevator at a time will be out of service so that any disruptions are kept to an absolute minimum."

The upgrade's major feature is installation of a new computerized operating system. "The elevators are

now operated through a series of mechanical relays," Bowen explains. "The computerized system will provide a better tracking system. If an elevator stops and needs repair, for example, maintenance will be automatically notified where a problem exists as soon as it occurs." Another feature will allow automatic notification of passengers in an elevator that's being averted to respond to a Code Blue emergency. "It will be a digital notification through the computer," Bowen says. "In the older elevators there's no way for passengers to know that the elevator they're on is being rerouted to respond to those emergencies."

While elevator car speed will

remain about the same, users will see quicker response time because of more efficient operations. Only one elevator will respond to each press of the call button, for example. "At night and on weekends all the elevators currently 'park' on one floor," Bowen adds. "Under the computerized system, we can stagger 'parking places' for the elevators and the closest car can respond to each call."

Repairs will also become easier, since these upgrades are the first for the elevators original to the 42-year-old Clinical Center. "It is getting harder to find replacement parts for the existing elevators," Bowen says.

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1

**Grand Rounds
noon-1 p.m.
Lipsett Amphitheater**
Treatment of Hepatitis C,
Jay H. Hoofnagle, M.D.,
NIDDK; *Adoptive Cell and
Gene Transfers for HIV
Infection,* Robert Walker, M.D.,
NIAID

**Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium**
*The 3-D Structure of DNA
Photolyase: How Light
Repairs DNA,* Johann
Deisenhofer, Ph.D., University
of Texas Southwestern Medical
Center at Dallas. Hosted by the
Structural Biology Interest
Group

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**Grand Rounds
noon-1 p.m.
Lipsett Amphitheater**
*IL-2 in HIV Infection: Does It
Have a Role?* Joseph Kovacs,
M.D., CC; *Clinical and
Biochemical Manifestations of
Depression: Relationship to
the Neurobiology of Stress,*
Philip W. Gold, M.D., NIMH

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**Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium**
*Avoiding a Train Wreck: What
Happens When RNA
Polymerase and DNA
Polymerase Collide,* Bruce M.
Alberts, Ph.D., president,
National Academy of Sciences.
Hosted by the Drosophila
Interest Group

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**Grand Rounds
noon-1 p.m.
Lipsett Amphitheater**
*A Collaborative Approach to
Hereditary Skin Disease:
Understanding Epidermolytic
Hyperkeratosis,*
Sherrie Bale, Ph.D., and John J.
DiGiovanna, M.D., NIAMS

**Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium**
*DNA Repair, Transcription, and
Chromatin Structure: An
Intimate Engagement,* Dirk
Bootsma, Ph.D., Erasmus
University, Rotterdam. Hosted
by the DNA Repair Interest
Group

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**Grand Rounds
noon-1 p.m.
Lipsett Amphitheater**
*Bench to Bedside:
Mastocytosis and the Mast
Cell,* Dean Metcalfe, M.D.,
NIAID

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**Wednesday Afternoon
Lecture
3 p.m.
Masur Auditorium**
*Genetic Control of
Programmed Cell Death in C.
elegans,* H. Robert Horvitz,
Ph.D., Massachusetts Institute
of Technology. Hosted by the
Apoptosis Interest Group

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**Clinical Staff Conference
noon-1:30 p.m.
Lipsett Amphitheater**
*Recent Advances in
Transplantation,* Robert A.
Goldstein, M.D., Ph.D.,
NIAID, moderator

**Wednesday Afternoon
Lecture
3 p.m.
Masur Auditorium**
*Mechanisms of
Transcriptional Regulation:
Assembly of Activator, Co-
activator, and TAF Complexes,*
Robert Tjian, Ph.D., University
of California at Berkeley.
Hosted by the Molecular
Biology Interest Group